

Racial Differences in the Willingness to Use Hospice Services

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ABSTRACT

Objective: This study assesses whether racial differences exist in the willingness to use hospice services in the future among black and white adults and potential factors that may contribute to such differences.

Methods: Data were collected from the City of Cincinnati component of the Greater Cincinnati Survey. A total of 510 random-digit-dialed telephone interviews were completed, with 473 adults included in the analyses (220 blacks, 253 whites).

Results: Relative to whites, blacks were significantly less likely to consider using hospice if they were near the end of life because of a terminal illness and less likely to do so even if their doctor strongly recommended its use. This reluctance was related to their prior exposure to hospice as well as their trust in their doctor to make the right end-of-life care decisions. Like whites, blacks who had a positive prior exposure to hospice were more willing to consider using hospice than those who have not been exposed to hospice, but only for those blacks who trust their doctor. For blacks who do not trust their doctor, those with prior hospice exposure, regardless of their level of satisfaction, were less willing to consider hospice than those without prior exposure.

Conclusions: Efforts to increase utilization of hospice services among blacks requires greater insight into the experiences that they have with hospice services for their family members and friends as well as their level of trust in their physician's decision making about end-of-life care.

INTRODUCTION

HOSPICE REMAINS an underused resource for dying patients despite its rapid growth and acceptance.¹⁻³ In particular, minority Americans are at greatest risk for underutilization of hospice care.^{4,5} Racial and ethnic minorities represent only 5%–7% of the hospice patient population.⁶ Blacks have 40% lower hospice use than whites,^{7,8} although recent evidence suggests that this gap may be closing.⁹ Some researchers argue that these differences result from hard-to-measure socioeconomic factors, variations in insurance coverage, job or familial obligations, limited geographical access to hospice care, less at-home caregiver support, and lack of a primary care physi-

cian for hospice referral.^{4,8,10-13} Others suggest that economic, educational, and access-to-care differentials between blacks and whites are not the primary explanation.⁸ There may be other important causes, such as differential care preferences, differences in knowledge to seek out or accept hospice care,⁶ overt racial bias at the individual or institutional level,¹⁴ differential treatment based on racial/ethnic stereotyping or discrimination,¹⁴ and language or other cultural barriers.⁸ Mistrust, also hypothesized to be a prominent barrier for blacks,^{6,15} may flourish most within a setting where the cultural/racial background of health care workers is not the same as the patient's.¹⁶

Given its philosophy, and the makeup of its workforce, hospice may be a foreboding place for blacks.¹⁵

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Although a majority of all Americans would prefer to die at home,^{17,18} 62% of blacks would prefer to die in the hospital.¹⁹ Blacks reportedly have lower interest in and knowledge of hospice care than whites.^{6,11,20} There may also be a lack of agreement with the hospice philosophy among blacks.¹⁵ Blacks see longevity as an intrinsic good,²¹ are reluctant to discuss advance directives,²² prefer curative care,²³ and hesitate to welcome strangers from hospice into their homes.²⁴

While there are a number of proposed explanations for the differences between blacks and whites in hospice utilization, there is a lack of empirical evidence on which to base educational and outreach efforts to reduce the differences. There are no studies that examine differences in attitudes about considering hospice care in the future among a population-based sample of community residents who do not have a life-threatening illness. This study assesses whether racial differences exist in the willingness to use hospice services in the future among black and white residents of a large Midwestern city, and potential factors that may contribute to such differences.

METHODS

Data collection

Data were collected in spring 2005 from questions added to the City of Cincinnati component of the Greater Cincinnati Survey. This random digit dialed telephone survey of about 1500 adults (age 18+ years) in the four Ohio, one Indiana, and three Kentucky counties surrounding Cincinnati is conducted semiannually by the University of Cincinnati Institute for Policy Research. Of the approximate 253,000 adult residents of Cincinnati, 57.5% are white, 37.6% are black or African American, and 5.0% are of other racial backgrounds.²⁵

Forty-one interviewers (19 black, 21 white, 1 Asian) conducted the survey. Each interviewer was trained by a full-time Field Director in survey research methods, computer/CATI interviewing and navigation, and the specific nature of this project. Interviewers read a standardized interview protocol to respondents using the WinCati Computer Aided Telephone Interviewing system. Respondent questions about individual survey items were first addressed by the interviewers using a prepared script and, if necessary, referred to supervisors. The questions were pretested 1 to 2 weeks prior to the conduct of the survey using a minimum of 20 interviews. None of the survey questions used in this study was modified based on these pretest interviews.

There were no additional validity/reliability checks of the survey questions. The data were weighted to be representative of the demographic profile of the city.

Measures

The survey questions used to measure the following constructs are presented in Table 1. Given the absence of previous research related to willingness to use hospice services, the questions were generated by the authors except where noted in Table 1.

Willingness to use hospice. Willingness to use hospice services was assessed by two questions (Questions 1 and 2, Table 1). Answers to Question 1 were operationally defined as a dichotomous variable: yes (definitely yes, probably yes) and no (definitely not, probably not, don't know). Respondents who provided a response other than yes to Question 1 were then asked Question 2. Answers to these two questions were combined into a trichotomous variable to describe willingness to use hospice in the future: yes (definitely yes/probably yes from Question 1), yes if doctor recommended (definitely yes/probably yes from Question 2), and no/don't know (definitely not/probably not/don't know from Question 2).

Previous hospice exposure. Previous exposure to hospice care was determined by a single item (Question 3, Table 1) categorized into a yes, no/don't know dichotomous variable.

Satisfaction with previous hospice care. Satisfaction with previous exposure to hospice care was measured by a single item (Question 4, Table 1). Responses were categorized into a dichotomous measure: yes (very satisfied, somewhat satisfied) and no (neither satisfied nor dissatisfied, somewhat dissatisfied, very dissatisfied, don't know).

Previous hospice experience. Responses to Questions 3 and 4 were combined to create a trichotomous summary variable to describe previous hospice experience: no prior exposure (no/don't know from Question 3), prior exposure—not satisfied (no/don't know from Question 4), and prior exposure—satisfied (yes from Question 4).

Attitude toward end-of-life care. Responses to Question 5 (Table 1) were categorized into an agree/not agree dichotomous variable, with don't know responses included in the not agree category.

TABLE 1. SURVEY QUESTIONS AND POSSIBLE RESPONSE CATEGORIES

<i>Question</i>	<i>Response categories</i>
1. Willingness to Use Hospice: If you were near the end of life because of a terminal illness, would you consider using hospice care?	Definitely Yes, Probably Yes, Probably Not, Definitely Not, Don't Know
2. Willingness to Use Hospice: Would you use hospice care if your doctor strongly recommended it?	Definitely Yes, Probably Yes, Probably Not, Definitely Not, Don't Know
3. Previous Hospice Exposure: Have you, a family member, or close friend ever used hospice care?	Yes, No, Don't Know
4. Satisfaction with Previous Hospice Care: How satisfied were you with the quality of hospice care that was received?	Very Satisfied, Somewhat Satisfied, Neither Satisfied Nor Dissatisfied, Somewhat Dissatisfied, Very Dissatisfied, Don't Know
5. Attitude toward End-of-Life Care: If I was terminally ill, I would want everything done to keep me alive as long as possible . . . do you agree or disagree? ^a	Strongly Agree, Agree, Disagree, Strongly Disagree, Don't Know
6. Patient-Physician Interpersonal Relationship: I trust my doctor to make the right decision about my health care if I were to get very sick . . . do you agree or disagree? ^b	Strongly Agree, Agree, Disagree, Strongly Disagree, Don't Know
7. Patient-Physician Interpersonal Relationship: I worry my doctor might want to stop treatments or "pull the plug" too soon if I were very sick . . . do you agree or disagree? ^b	Strongly Agree, Agree, Disagree, Strongly Disagree, Don't Know
8. Health Care Power of Attorney: Have you heard about a health care power of attorney in which you name someone to make decisions about your health care in the event you become seriously ill? and, if so, have you completed this? ^c	Have Heard About and Completed, Have Heard About But Not Completed, Have Not Heard About, Don't Know

^aSource: Ethnicity and Attitudes toward Advance Care Directives Questionnaire.²⁸

^bSource: Advanced Care Planning survey questionnaire.²⁹

^cSource: AARP North Carolina End of Life Care Survey.³⁰

Patient-physician interpersonal relationship. This measure was assessed by two items (Questions 6 and 7, Table 1). Responses to both questions were categorized into agree/not agree dichotomous variables, with don't know responses included in the not agree category.

Health care power of attorney. This measure was assessed by a single item (Question 8, Table 1) categorized into a trichotomous variable (heard about—completed, heard about—not completed, not heard about), with don't know responses included in the latter category.

Demographic characteristics. The Greater Cincinnati Survey routinely collects data on the demographics characteristics of respondents. The primary vari-

ables included in the analysis included race (black, white), age (18–29, 30–9, 50–4, 65+), gender (male, female), education (less than high school, high school graduate, some college, college graduate), marital status (married, widowed, divorced/separated, never married), household income (less than \$15,000, \$15,000 to \$29,999, \$30,000 to \$44,999, \$45,000+), number of adults in the household (one, two, three or more), and number of children in the household (none, one, two, three or more). The small number of respondents with a race other than black or white (20) or of unknown race (17) was omitted from the analysis. Thus, the final sample size for the analysis was 473 of the 510 completed interviews. Missing values for household income were replaced with predicted values from a regression equation based on race, gender, education, marital status, number of adults and children in the household, home ownership, and employment sta-

TABLE 2. DEMOGRAPHIC CHARACTERISTICS BY RACE^a

<i>Demographic characteristic</i>	<i>White (%)</i>	<i>Black (%)</i>	<i>Total (%)</i>	<i>p value^b</i>
Age				0.0019
18–29	26.6	34.2	29.6	
30–49	34.8	40.1	36.9	
50–64	16.6	16.9	16.7	
65+	22.0	8.8	16.7	
Gender				0.1524
Male	48.3	41.7	45.6	
Female	51.7	58.3	54.4	
Education				0.0002
Less than high school graduate	23.6	23.0	23.3	
High school graduate	22.7	31.4	26.2	
Some college/technical school	23.0	31.6	26.4	
College graduate	30.7	14.0	24.0	
Marital Status				0.0004
Married	43.4	27.6	37.0	
Widowed	10.6	6.8	9.1	
Separated/divorced	15.1	19.8	17.0	
Never Married	30.8	45.8	37.0	
Income				<0.0001
\$0–\$14,999	15.5	25.7	19.5	
\$15,000–\$29,999	21.4	33.5	26.2	
\$30,000–\$44,999	20.4	21.0	20.6	
\$45,000+	42.6	19.9	33.7	
Adults in the Household				0.0008
One	22.0	37.9	28.4	
Two	51.0	40.6	46.8	
Three or more	27.0	21.4	24.8	
Children in the Household				0.0001
None	66.2	49.9	59.7	
One	17.9	22.9	19.9	
Two	10.4	10.7	10.5	
Three or more	5.6	16.4	9.9	

^aBlack $n = 220$ (weighted $n = 195$); White $n = 253$ (weighted $n = 289$); Total $n = 473$ (weighted $n = 484$).

^bProbability of rejecting the null hypothesis of no differences between whites and blacks based on χ^2 test of significance.

tus. This reduced the number of case-wise deletions in the regression analyses from 107 to 65 respondents.

Analysis

All analyses were conducted using the SAS 8.0 statistical package (SAS Institute, Cary, NC) and performed in three phases. First, the univariate distributions of all variables were examined. This step included the necessary transformations of variables and construction of all composite measures for constructs that used multiple items (e.g., prior hospice experience). Second, the bivariate associations between the willingness to use hospice variables and the other variables as well as all of the variables and race (black/white) were examined using contingency table analyses.

Third, logistic regression techniques were conducted to assess the relative strength of various individual variables, particularly race, on the willingness to use hospice measure while statistically controlling

for the other variables. Analyses were performed using the first “willingness to use hospice” question as the dependent variable. To assess whether a particular variable had a differential effect on the willingness to use hospice depending on race, the final model was reanalyzed to include interaction terms between each variable and race.

Additional analyses were performed to assess any influence from combining “don’t know” with other response categories for some survey items (see Measures section). Excluding the “don’t know” responses did not result in any significant changes in the results or conclusions.

RESULTS

Sample characteristics

The sample consisted of 59.7% white and 40.3% black adults (Table 2). Except for gender, there were

TABLE 3. END-OF-LIFE VARIABLES BY RACE^a

<i>End-of-life variables</i>	<i>White (%)</i>	<i>Black (%)</i>	<i>Total (%)</i>	<i>p value^b</i>
Willingness to use hospice				<0.0001
Yes	89.0	70.9	81.7	
Yes, if doctor recommends	6.1	10.5	7.9	
No/don't know	4.9	18.6	10.4	
Previous exposure to hospice				0.0416
Yes	58.9	49.3	55.0	
No	41.1	50.7	45.0	
Satisfaction with hospice ^c				0.0183
Yes	91.7	81.8	88.2	
No/don't know	8.3	18.2	11.8	
Alive as long as possible				<0.0001
Yes	14.1	48.8	28.0	
No/don't know	85.9	51.2	72.0	
Trust doctor to make right decision				0.5385
Yes	75.1	77.6	76.1	
No/don't know	24.9	22.4	23.9	
Worry doctor stop treatments				0.0135
Yes	25.7	36.4	30.0	
No/don't know	74.3	63.6	70.0	
Health care power of attorney				0.0427
Heard about, completed	35.2	24.9	31.0	
Heard about, not completed	50.9	61.4	55.1	
Not heard about/don't know	13.9	13.7	13.8	

^aBlack $n = 220$ (weighted $n = 195$); White $n = 253$ (weighted $n = 289$); Total $n = 473$ (weighted $n = 484$).

^bProbability of rejecting the null hypothesis of no differences between whites and blacks based on χ^2 test of significance.

^cPercentages based on number of respondents who had previous use of hospice care.

significant differences in the demographic characteristics between black and white adults. Compared to whites, blacks were more likely to be younger, have lower household incomes, be the only adult in the household, and have three or more children in the household. Blacks were less likely to be college graduates, married, and living in a household with no children.

Bivariate results

While a number of end-of-life variables showed differences between blacks and whites from simple bivariate analyses (Table 3), only two associations remained significant after adjusting for demographic characteristics: willingness to use hospice, and attitude toward end of life care.

Willingness to use hospice. Whites were significantly more likely than blacks to consider using hospice care if they were near the end of life because of a terminal illness (89.0% versus 70.9%). Of those who would not consider using hospice care, 55.5% of whites and 36.0% of blacks would change their mind if their doctor strongly recommended using hospice care. Overall, 95.1% of whites and 81.4% of blacks were willing to use hospice for end-of-life care after

factoring in a doctor's recommendation. After adjusting for the differences in demographic characteristics between blacks and whites, blacks were still significantly less likely than whites to consider using hospice care independent of their doctor's recommendation (odds ratio [OR] = 0.30, 95% confidence interval [CI]: 0.16–0.58), and after taking into consideration their doctor's recommendation (OR = 0.38, 95% CI: 0.11–0.61).

Attitude toward end-of-life care. Blacks were significantly more likely than whites (48.8% versus 14.1%) to want everything done to keep them alive as long as possible. These differences remained significant after adjusting for differences in the demographic characteristics (OR = 6.52, 95% CI: 3.56–11.94).

Logistic regression results

After controlling for the demographic and end-of-life related variables, blacks were significantly less likely than whites to consider using hospice care if they were near the end of life because of a terminal illness (Table 4). Also, respondents who were satisfied with the quality of prior hospice care were more likely to consider using hospice if they were at the end of life compared with those who did not have a pre-

TABLE 4. LOGISTIC REGRESSION RESULTS

<i>Variable</i>	<i>Estimate</i>	<i>p value</i> ^a
Race (ref: white)		
Black	-1.1751	0.0004
Age (ref: 18-29)		
30-49	-0.2434	0.5506
50-64	0.0745	0.8885
65-99	-0.1047	0.8768
Gender (ref: male)		
Female	-0.1707	0.5873
Education (ref: high school)		
<High school	0.1922	0.6545
Some college/technical school	-0.4735	0.2130
College graduate	-0.1677	0.7122
Marital status (ref: married)		
Widow	1.6225	0.0330
Divorced/Separated	1.9892	0.0004
Never married	1.3638	0.0047
Income (ref: \$45,000+)		
<\$15,000	-1.2597	0.0281
<\$15,000-\$29,999	-1.0240	0.0355
\$30,000-\$44,999	-0.7786	0.0831
Adults in household (ref: one)		
Two	0.6807	0.0907
Three or more	0.7370	0.1007
Children in the household (ref: none)		
One	0.0232	0.9555
Two	-0.4584	0.3702
Three or more	-0.5836	0.2087
Previous hospice experience (ref:		
Yes—Satisfied	0.8847	0.0074
Yes—Not satisfied	-0.8863	0.1035
Aggressive care (ref: no)		
Yes	0.2927	0.3835
Power of attorney (ref: not heard)		
Completed	0.7929	0.1020
Not completed	0.3908	0.3507
Trust doctor (ref: no)		
Yes	0.8194	0.0136
Worry doctor stop (ref: no)		
Yes	0.1062	0.7489

^aProbability that the estimated regression coefficient is significantly different from zero.

vious hospice exposure or who were not satisfied with the quality of hospice care. Similarly, respondents who trust their doctor to make the right decisions about their end-of-life care were more likely to consider hospice care than those who do not have this trust.

The effect of race on the willingness to use hospice care was moderated by significant interactive effects with prior exposure to hospice and physician trust. Figure 1 illustrates the relationships between race, exposure to hospice care, and physician trust. For white respondents and for blacks who expressed trust in their doctor, exposure to hospice was associated with an overall increase in willingness to use hospice in the future. However, for blacks with low trust in their doctor, the opposite association occurred: prior exposure

to hospice care was associated with less willingness to consider hospice in the future.

While a significant interaction effect was found between race and satisfaction with prior exposure to hospice, the effect was an artifact due to the zero number of whites not trusting their doctor and not being satisfied. Dissatisfaction with previous hospice exposure resulted in a significant decrease in the willingness of blacks to consider hospice services in the future, with physician trust having a significant effect on the level of willingness. For blacks who do not trust their doctor, only 13.3% of those who were not satisfied would be willing to consider hospice in the future, compared to 49.0% who were satisfied. Similarly, for blacks who do trust their doctor, 41.4% of those who were not sat-

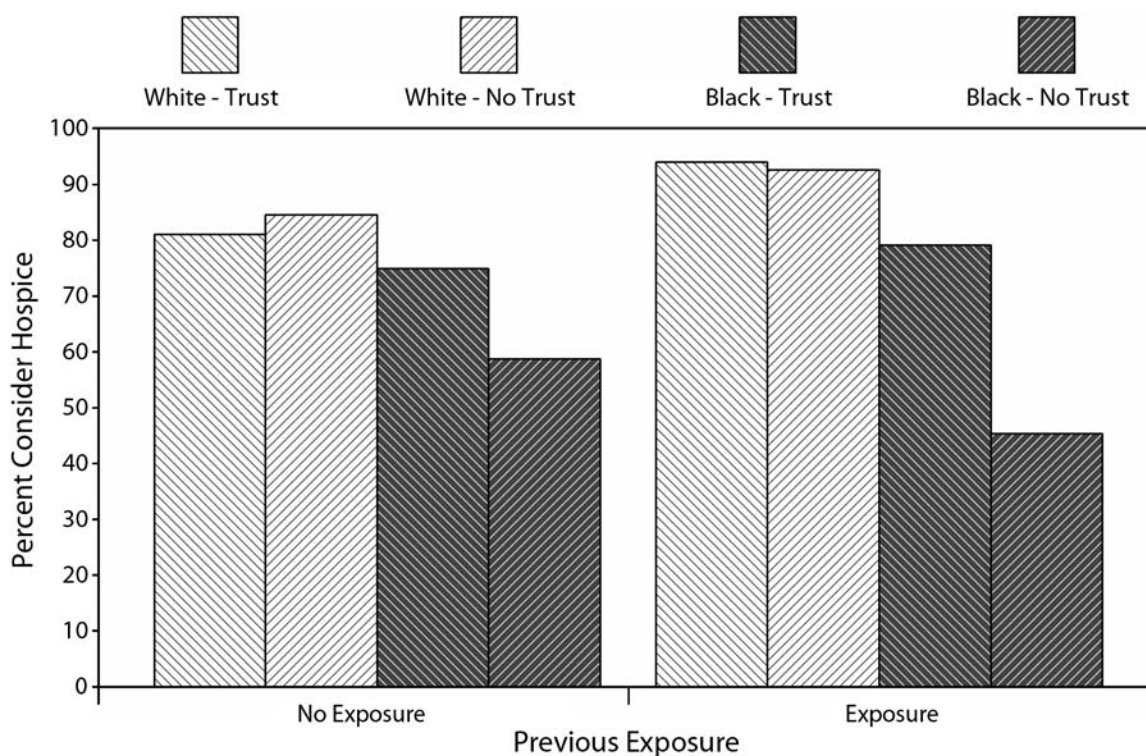


FIG. 1. Consider using hospice by prior exposure for whites and blacks, with and without trust in doctor.

isfied would consider hospice in the future as compared to 89.0% who were satisfied.

In addition, the regression analyses found that unmarried persons were more likely to consider using hospice for end of life care than married persons. Low income persons, particularly those with household incomes less than \$30,000 annually, were less willing than higher income persons to use hospice in the future.

DISCUSSION

The study findings are consistent with the literature suggesting that blacks not only underutilize hospice services, but also may have a lower level of interest in hospice care. Relative to whites, blacks in this study were significantly less likely to consider using hospice if they were near the end of life because of a terminal illness and less likely to do so even if their doctor strongly recommended its use.

The reluctance of blacks to consider hospice care varied with previous exposure to hospice as well as trust in their doctor to make the right end-of-life decisions. Blacks who trust their doctor to make the right decisions may view hospice care in a manner similar to whites, whose willingness to use hospice appears to

be independent of the level of physician trust. Not surprisingly, prior positive exposure to hospice corresponded to a greater willingness to consider hospice in the future, and prior negative exposure was associated with less willingness.

Blacks who do not trust their doctor's decision-making may view choices to use hospice differently. Those who have not had *a priori* exposure to hospice may be more willing to consider hospice for end-of-life care than those who have prior experience with hospice—even if it was a positive experience. One might assume that a baseline mistrust of physicians may negatively skew a subsequent experience with hospice and the willingness to use hospice in the future. However, the opposite cause and effect relationship may be true—that a prior experience with hospice, whether positive or negative, somehow reinforces a lack of trust in physician decision-making. Further research is planned to explore the relationships between physician trust, experience with hospice, and the willingness to consider hospice in the future.

For a number of end-of-life variables, the bivariate differences between blacks and whites became statistically insignificant after adjusting for differences in the demographic characteristics. This implies that it may not have been race *per se* that influenced responses to these end-of-life care questions, but socio-

economic and demographic characteristics. Further research is required to better understand the influence of race, as well as other potential predisposing variables, on end-of-life care attitudes and behaviors.

One study limitation is that the subjects consisted only of City of Cincinnati residents, and their associated experiences were probably limited to the hospice services predominately located within or in close proximity to the city. Thus, the results may not be generalizable to racial/ethnic populations in other sectors of the United States or nationally. It is uncertain whether study respondents are typical in their prior experiences with hospice services as well as their relationships with their primary care physicians. Also, it is not known whether reported reluctance to use hospice services in the future actually translates into decreased use of such services when the person is in an end-of-life care situation. However, the study findings are not unexpected given the reported literature on racial/ethnic minority utilization of hospice services.

The study is also limited by the size of this initial survey. For example, interactions between race and prior hospice exposure, satisfaction, and physician trust were statistically significant, but included some subgroups with small numbers of respondents. A larger study is needed to verify the interactions observed, and to explore other possible confounders of the relationships between these variables.

This is the first study to examine the relationships between physician trust, satisfaction with prior hospice exposure, and likelihood of future use of hospice services. The findings may help inform patient education efforts to ensure equitable access and utilization of hospice services for minority populations. The results of this exploratory study are consistent with other studies related to potential disparities between racial groups, both in the willingness to consider hospice care and the satisfaction with hospice care experiences. Efforts to increase utilization of hospice services by blacks, and other racial/ethnic minorities, requires greater insight into the prior experiences with hospice care, as well as their trust in their primary care physician's decision-making about end-of-life care.

A recent demonstration project to improve home-based palliative care for chronically ill patients led to an increase in the number of African American patients who accessed hospice care.²⁶ Home health providers in the study program provided information about end-of-life care options while developing a continuity care relationship at home with patients. With particular attention to potential barriers such as lack of trust in physician decision-making and prior unsatisfactory experiences with hospice, community-based

outreach programs may find even greater success in improving rates of hospice utilization and decreasing disparities in care.

The study findings can also inform physicians as they discuss end of life care options with their patients. Physicians often miss opportunities to offer hospice as an option to terminally ill patients, particularly those with end stage chronic illnesses other than cancer.²⁷ The first step is for physicians to open a dialogue with their patients regarding end-of-life care options as patients progress toward more severe, end-stage chronic disease. When hospice care is presented as an option, physicians should ask patients about preconceived notions of hospice care, previous experiences with hospice care, and fears or concerns related to the appropriateness and timing of hospice care. This approach may help ensure that physicians and their patients are knowledgeable of each other's perspectives and that patients are confident that their physicians will make decisions consistent with their wishes. A greater understanding of factors that influence attitudes about hospice care will help inform these discussions, as well as efforts to educate communities about care options near the end of life.

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